**Return of Organization Exempt From Income Tax** 

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

▶ Do not enter Social Security numbers on this form as it may be made public.

► Information about Form 990 and its instructions is at www irs gov/form990

Α	For the	e 2013 calendar year, or tax year beginning and	ending				
В	Check if applicabl	C Name of organization		D Employer identifi	cation number		
Г	Addre chang	THE BARTH SYNDROME FOUNDATION, INC.					
	Name chang			22-3	755704		
	Initial return	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	E Telephone numbe			
	Termir ated	P.O. BOX 618		914-	834-1771		
	Ameno	City or town, state or province, country, and ZIP or foreign postal code		<b>G</b> Gross receipts \$	1,069,130.		
	Applic	HARCIMONI, NI 10550		H(a) Is this a group re			
	pendir	F Name and address of principal officer: LINDSAY B. GROFF		for subordinates	? Yes X No		
		SAME AS C ABOVE		H(b) Are all subordinates in	ncluded? Yes No		
		empt status: $X = 501(c)(3) = 501(c)(0)$ (insert no.) $4947(a)(1)$	or 527	,	list. (see instructions)		
		te: WWW.BARTHSYNDROME.ORG		H(c) Group exemptio			
		organization: X Corporation Trust Association Other	<b>∟</b> Year	of formation: 2000 N	M State of legal domicile: DE		
P	art I	Summary	O BROW		GG OF DARMI		
e S	1			OTE AWARENE			
Jan		SYNDROME; 2) TO EDUCATE AND SUPPORT PHYS		-			
Activities & Governance	1	Check this box if the organization discontinued its operations or dispo		1	ssets.		
Ĝ				<u>3</u>	10		
<u>«</u>		Number of independent voting members of the governing body (Part VI, line 1b)			4		
ij		Total number of individuals employed in calendar year 2013 (Part V, line 2a)			20		
ξį	72	Total number of volunteers (estimate if necessary)			0.		
ĕ		Net unrelated business taxable income from Form 990-T, line 34			0.		
_		Not diffolded business taxable from to first out out 1, fine or		Prior Year	Current Year		
a)	8	Contributions and grants (Part VIII, line 1h)		871,480.	824,480.		
ņ		Program service revenue (Part VIII, line 2g)		0.	0.		
Revenue	1	Investment income (Part VIII, column (A), lines 3, 4, and 7d)		7,975.	175.		
Œ		Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		0.	0.		
	1	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)		879,455.	824,655.		
		Grants and similar amounts paid (Part IX, column (A), lines 1-3)		315,823.	297,772.		
	1	Benefits paid to or for members (Part IX, column (A), line 4)		0.	0.		
Se	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		412,284.	-		
Expenses	16a	Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.		
ğ	b	Total fundraising expenses (Part IX, column (D), line 25)	<u>41.                                      </u>				
ш	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		228,202.	62,360.		
		Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		956,309.	796,952.		
- "	19	Revenue less expenses. Subtract line 18 from line 12		-76,854.	27,703.		
Net Assets or Fund Balances			Ве	ginning of Current Year	End of Year		
Sse	20	Total assets (Part X, line 16)		1,909,785.	1,908,550.		
let A	21	Total liabilities (Part X, line 26)		90,438. 1,819,347.	62,293.		
	22 art II	Net assets or fund balances. Subtract line 21 from line 20		1,013,347.	1,040,237.		
		Ities of perjury, I declare that I have examined this return, including accompanying schedule	ac and etatem	ente and to the heet of m	v knowledge and helief it is		
		t, and complete. Declaration of preparer (other than officer) is based on all information of w			y knowledge and boller, it is		
	, 001100	that complete social and of property (care that office) is seed on an information of the	mon proparor	Indo any knownougo.			
Sig	n	Signature of officer		Date			
He		LINDSAY B. GROFF, EXECUTIVE DIRECTOR					
	_	Type or print name and title					
		Print/Type preparer's name Preparer's signature		Date Check	PTIN		
Pai	d	MICHAEL L. CECERE		04/14/14 if self-employ	P00236848		
Pre	parer	Firm's name GRAY, GRAY & GRAY, LLP		Firm's EIN	04-2088368		
Use	Only	Firm's address 34 SOUTHWEST PARK					
		WESTWOOD, MA 02090-1548		Phone no. (7			
Ma	v the II	RS discuss this return with the preparer shown above? (see instructions)			X Yes No.		

Pa	rt III Statement of Program Service Accomplishments
	Check if Schedule O contains a response or note to any line in this Part III
1	Briefly describe the organization's mission:
	THE BARTH SYNDROME FOUNDATION IS AN ENGAGED, GLOBAL COMMUNITY WHOSE
	MISSION IS SAVING LIVES THROUGH EDUCATION, ADVANCES IN TREATMENT, AND
	FINDING A CURE FOR BARTH SYNDROME.
	Did the organization undertake any significant program services during the year which were not listed on
2	V V.
	the prior Form 990 or 990-EZ?  If "Yes," describe these new services on Schedule O.
3	Did the organization cease conducting, or make significant changes in how it conducts, any program services?  Yes X No
_	If "Yes," describe these changes on Schedule O.
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.
	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and
	revenue, if any, for each program service reported.
4a	(Code:) (Expenses \$ 437,806 • including grants of \$ 297,772 • ) (Revenue \$)
	THE BARTH SYNDROME SCIENCE, MEDICINE & RESEARCH PROGRAM IN 2013 WAS
	COMPRISED OF A) THE BSF RESEARCH GRANT PROGRAM TO FOSTER SCIENTIFIC AND
	CLINICAL INVESTIGATIONS INTO BARTH SYNDROME TO FACILITATE THE
	DEVELOPMENT OF A SPECIFIC TREATMENT OR A CURE FOR THIS DISEASE, AND B)
	THE BARTH SYNDROME MEDICAL DATABASE AND BIO-REPOSITORY FOR THE
	COLLECTION AND STORAGE OF MEDICAL INFORMATION/SAMPLES ON INDIVIDUALS
	WITH BARTH SYNDROME OVER TIME TO GAIN A BETTER UNDERSTANDING OF THE DISEASE.
	DISEASE.
4b	(Code: ) (Expenses \$ 92,342 • including grants of \$ ) (Revenue \$ )
	THE BSF COMMUNICATIONS PROGRAM IS COMPRISED OF BI-ANNUAL NEWSLETTERS IN
	THE SPRING AND THE FALL OF EACH YEAR, AND ANNUAL REPORT, AN UPDATED
	HEALTHCARE BROCHURE, AND VARIOUS POSTCARD MAILINGS PROMOTING THE BSF
	INTERNATIONAL CONFERENCE AND OTHER KEY EVENTS.
4c	(Code: ) (Expenses \$ 103,482 • including grants of \$ ) (Revenue \$ )
40	(Code: ) (Expenses \$ 103,482. including grants of \$ ) (Revenue \$ ) (Revenue \$ TAMILY SERVICES PROGRAM INCLUDES A ROBUST WEBSITE WHICH ALLOWS USERS TO
	ACCESS THE LATEST RESOURCES; FAMILY OUTREACH SERVICES TO ENCOURAGE
	AFFECTED FAMILIES TO GET TOGETHER; A LISTSERV WHERE FAMILIES SUPPORT
	ONE ANOTHER, AS WELL AS PERSONAL PHONE CALLS TO WELCOME NEW FAMILIES
	AND TO OFFER NON-MEDICAL SUPPORT WHEN NEEDED.
4d	Other program services (Describe in Schedule O.)
	(Expenses \$ 30,592 • including grants of \$ ) (Revenue \$ )  Total program service expenses ► 664,222 •
<u>4e</u>	Total program service expenses 664,222.

332002 10-29-13

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### Part IV | Checklist of Required Schedules

			Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?			
	If "Yes," complete Schedule A	1	<u> </u>	
2	Is the organization required to complete Schedule B, Schedule of Contributors?	2	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3		х
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect			
	during the tax year? If "Yes," complete Schedule C, Part II	4		_X_
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		Х
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to			
	provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,			
	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		_X_
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8		х
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for			
	amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services?  If "Yes," complete Schedule D, Part IV	9		Х
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent			
	endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V	10		_X_
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D,			
	Part VI	11a		_X_
b	Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b		Х
С	Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total			
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		_X_
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in			7.7
	Part X, line 16? If "Yes," complete Schedule D, Part IX	11d		X_
	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e		Х
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses			х
100	the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X  Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete	11f		
ıza	Schedule D, Parts XI and XII	12a	Х	
b	Was the organization included in consolidated, independent audited financial statements for the tax year?	124		
-	If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		Х
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business,			
	investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000			
	or more? If "Yes," complete Schedule F, Parts I and IV	14b	X	
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any			
	foreign organization? If "Yes," complete Schedule F, Parts II and IV	15	X	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to			v
4-	or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		_X_
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,			Х
19	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I  Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines	17		
18	1c and 8a? If "Yes," complete Schedule G, Part II	18		Х
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes,"	10		
	complete Schedule G, Part III	19		Х
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		X
	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		

### Part IV Checklist of Required Schedules (continued)

			Yes	No
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or			
	government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21	Х	
22	Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		х
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current			
	and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete			
	Schedule J	23	X	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the			
	last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete			
	Schedule K. If "No", go to line 25a	24a		X
	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
С	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease			
	any tax-exempt bonds?	24c		
	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		_
<b>2</b> 5a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		x
h	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and	25a		
b	that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete			
	Schedule L, Part I	25b		х
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or			
	former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If so,			
	complete Schedule L, Part II	26		Х
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial			
	contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member			
	of any of these persons? If "Yes," complete Schedule L, Part III	27		X
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV			
	instructions for applicable filing thresholds, conditions, and exceptions):			
	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28a		X
	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28b		X
С	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer,	00-		х
00	director, trustee, or direct or indirect owner? If "Yes," complete Schedule L, Part IV  Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	28c 29	Х	
29 30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation	29	-25	
30	and the stine of It "Von " complete Schodule M	30		х
31	Did the organization liquidate, terminate, or dissolve and cease operations?			<del></del>
٥.	If "Yes," complete Schedule N, Part I	31		х
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete			
	Schedule N, Part II	32		Х
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			
	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		X
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and			
	Part V, line 1	34		X
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Х
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity			
00	within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		<del>                                     </del>
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization?	26		х
37	If "Yes," complete Schedule R, Part V, line 2  Did the organization conduct more than 5% of its activities through an entity that is not a related organization	36		<u> </u>
31	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		x
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	"		<del></del> -
	Note. All Form 990 filers are required to complete Schedule O	38	х	

### | Part V | Statements Regarding Other IRS Filings and Tax Compliance

	Check if Schedule O contains a response or note to any line in this Part V											
		<u></u>	Yes	No								
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1	1.00	140								
b		0										
С	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming	7										
	(gambling) winnings to prize winners?	. 1c	Х									
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,											
	filed for the calendar year ending with or within the year covered by this return 2a	4										
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	Х									
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)											
За	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X								
b	If "Yes," has it filed a Form 990-T for this year? If "No," to line 3b, provide an explanation in Schedule O	3b										
4a	4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a											
	financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		X								
b	If "Yes," enter the name of the foreign country: ►											
	See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.											
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		<u> </u>	X								
b	, , , , , , , , , , , , , , , , , , , ,			Х								
	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?	. <u>5c</u>	<u> </u>									
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit			<b>₩</b>								
	any contributions that were not tax deductible as charitable contributions?	<u>6a</u>	-	X								
D	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b										
7	were not tax deductible?  Organizations that may receive deductible contributions under section 170(c).	OD										
' а	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor	? 7a		х								
b	and the second s											
	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required											
	to file Form 8282?	. 7c		Х								
d	If "Yes," indicate the number of Forms 8282 filed during the year											
е	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e										
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?			<u> </u>								
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	. 7g	<u> </u>									
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C'	? 7h										
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting											
•	organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8										
9	Sponsoring organizations maintaining donor advised funds.	0-										
a	Did the organization make any taxable distributions under section 4966?  Did the organization make a distribution to a donor, donor advisor, or related person?	9a 9b										
10	Section 501(c)(7) organizations. Enter:	90										
а	Initiation fees and capital contributions included on Part VIII, line 12											
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b											
11	Section 501(c)(12) organizations. Enter:											
а	Gross income from members or shareholders 11a											
b	Gross income from other sources (Do not net amounts due or paid to other sources against											
	amounts due or received from them.)											
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a										
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	_										
13	Section 501(c)(29) qualified nonprofit health insurance issuers.											
а	Is the organization licensed to issue qualified health plans in more than one state?	13a										
_	<b>Note.</b> See the instructions for additional information the organization must report on Schedule O.											
b	Enter the amount of reserves the organization is required to maintain by the states in which the											
_	organization is licensed to issue qualified health plans  The who are some an head  13b											
	Enter the amount of reserves on hand  Did the exemplation receive any payments for indeed temping convices during the tay year?	446		X								
	Did the organization receive any payments for indoor tanning services during the tax year?  If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O	14a 14b	$\vdash$									
IJ	in res, has it lied a form report these payments: in rio, provide an explanation in obliedule of		n <b>990</b>	(2013)								

22-3755704

Form **990** (2013)

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

	Check if Schedule O contains a response or note to any line in this Part VI			X
Sec	tion A. Governing Body and Management			
			Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year 1a 10			
	If there are material differences in voting rights among members of the governing body, or if the governing			
	body delegated broad authority to an executive committee or similar committee, explain in Schedule O.			
b	Enter the number of voting members included in line 1a, above, who are independent 1b 10			
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other			
	officer, director, trustee, or key employee?	2	Х	
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision			
	of officers, directors, or trustees, or key employees to a management company or other person?	3		Х
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		Х
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5		Х
6	Did the organization have members or stockholders?	6		Х
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or			
	more members of the governing body?	7a		Х
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or			
	persons other than the governing body?	7b		Х
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:			
	The governing body?	8a	Х	
b	Each committee with authority to act on behalf of the governing body?	8b	Х	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the			
	organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9		Х
Sec	tion B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)			
			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		Х
	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates,			
	and branches to ensure their operations are consistent with the organization's exempt purposes?	10b		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	Х	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.			
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	Х	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Х	
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe			
	in Schedule O how this was done	12c	Х	
13	Did the organization have a written whistleblower policy?	13	Х	
14	Did the organization have a written document retention and destruction policy?	14	Х	
15	Did the process for determining compensation of the following persons include a review and approval by independent			
	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
а	The organization's CEO, Executive Director, or top management official	15a	Х	
	Other officers or key employees of the organization	15b	Х	
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a			
	taxable entity during the year?	16a		Х
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation			
	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's			
	exempt status with respect to such arrangements?	16b		
Sec	tion C. Disclosure			
17	List the states with which a copy of this Form 990 is required to be filed MA, NY, CT, NJ, IL, TN, PA, VA, CA			, UT
18	Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) and 990-T (Section 501(c)(3)s only) are	vailab	le	
	for public inspection. Indicate how you made these available. Check all that apply.			
	Own website  Another's website  Upon request  Other (explain in Schedule O)			
19	Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, an	d finar	ncial	
	statements available to the public during the tax year.			
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organiza	ion:		
	ELLEN BRUNO - 508-668-9392			
	92 MILL BROOK AVENUE, WALPPOLE, MA 02081-2163	_	000	(00:-:
332006	5 10-29-13 SEE SCHEDULE O FOR FULL LIST OF STATES	Form	990	(2013)

# Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

Check if Schedule O contains a response or note to any line in this Part VII

### Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

- 1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
  - List all of the organization's current key employees, if any. See instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

(A) Name and Title	(B) Average hours per	box	(C) Position (do not check more box, unless person officer and a directo				h an	(D) Reportable compensation	(E) Reportable compensation	(F) Estimated amount of
	week (list any hours for related organizations below line)	stee or director	Institutional trustee	Officer Officer	Key employee	Highest compensated employee	Ĺ	from the organization (W-2/1099-MISC)	from related organizations (W-2/1099-MISC)	other compensation from the organization and related organizations
(1) STEPHEN KUGELMANN BOARD MEMBER	2.00	x						0.	0.	0.
(2) KATHERINE MCCURDY	10.00	<del> </del>						•	0.	
BOARD MEMBER		x						0.	0.	0.
(3) SUSAN OSNOS	2.00									
BOARD MEMBER		Х						0.	0.	0.
(4) SUSAN WILKINS	2.00									
BOARD MEMBER		Х						0.	0.	0.
(5) RANDY BUDDEMEYER	5.00	ļ		l						
TREASURER	10.00	Х		Х				0.	0.	0.
(6) MARCUS SERNEL	10.00	ļ.,		٠,,					0	_
CHAIRMAN A MCCODMACK	2 00	Х		Х				0.	0.	0.
(7) SUSAN A. MCCORMACK SECRETARY	2.00	x		X				0.	0.	0.
(8) JOHN WILKINS	2.00	┢		^				0.	0.	· ·
BOARD MEMBER	2:00	x						0.	0.	0.
(9) DAVID AXELROD, M.D.	2.00	<del> </del>								
BOARD MEMBER		x						0.	0.	0.
(10) CATHY RITTER	2.00									
BOARD MEMBER		X						0.	0.	0.
(11) LINDSAY B. GROFF	40.00									
EXECUTIVE DIRECTOR				Х				110,308.	0.	0.
(12) MATTHEW TOTH	40.00	1				l				
DIR OF SCIENCE	40.00					X		143,781.	0.	7,209.
(13) VALERIE BOWEN	40.00	-					3,5	70 506	0	7 266
PRESIDENT, FORMER							Х	72,526.	0.	7,266.
		1								
	+	-				$\vdash$				
		1								
-	1					t				
		1								
						Ī				

	t VII Section A. Officers, Directors, Trus								•			701		age C
	(A)	(B)				C)	<u> </u>		(D)	(E)			(F)	
	Name and title	Average	(do		Pos		1 than	one	Reportable	Reportable		Es	timate	ed
		hours per	box	, unle	ss pe	rson	is bot	h an		compensation			nount	of
		week (list any	<b>—</b>	T		T	T	100,	from the	from related organizations			other pensa	ation
		hours for	direct				- D			(W-2/1099-MISC	2)		om th	
		related	tee or	ustee			ensate		(W-2/1099-MISC)	· ·		orga	anizat	ion
		organizations below	al trus	onal tr		loyee	comp						d relat	
		line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	rmer				orga	ınizati	ons
			드	드	6	ᇂ	王占	프			$\dashv$			
			ł											
											_			
											$\dashv$			
							-				$\dashv$			
			ł											
							$\vdash$				$\dashv$			
			l											
											$\dashv$			
			ŀ											
	Out total							Ļ	326,615.		0.	1.	4,4	75
	Sub-total Total from continuation sheets to Part V								0.		0.		<del>± , ±</del>	73.
	Total (add lines 1b and 1c)								326,615.		0.	1	4,4	
	Total number of individuals (including but r								· · · · · · · · · · · · · · · · · · ·	0.000 of reportable				
	compensation from the organization									, ,				2
													Yes	No
3	Did the organization list any former officer,			e, ke	ey er	mplo	yee	, or	highest compensated e	mployee on				
	line 1a? If "Yes," complete Schedule J for s	such individual										3	X	
4	For any individual listed on line 1a, is the su	•							•	the organization				
-	and related organizations greater than \$15									(al al. # a a		4	Х	
5	Did any person listed on line 1a receive or rendered to the organization? If "Yes," com	•				-			-			5		Х
Sec	etion B. Independent Contractors	ipiete deriedar	C 0 1	01 30	ucn	pers	3011					<u> </u>		
1	Complete this table for your five highest co	mpensated in	depe	ende	ent c	onti	racto	ors t	that received more than	\$100,000 of comp	ensa	ation f	rom	
	the organization. Report compensation for													
	(A)								(B)			(C		
	Name and business	address	N	INC	E				Description of s	services	C	omper	nsatio	n
								_						
								$\exists$						
								1						
2	Total number of independent contractors (	•	ot li	mite	d to		se li: 0	stec	d above) who received n	nore than				
	THE THE REPORT OF COMPANY AND TRANSPORTED AND A COMPANY AN	zarion 🖶				,	u			1				

Ра			Check if Schedule O cont		nse (	or note to any lin	e in this Part VIII			
							<b>(A)</b> Total revenue	(B) Related or exempt function revenue	<b>(C)</b> Unrelated business revenue	( <b>D)</b> Revenue excluded from tax under sections 512 - 514
Contributions, Gifts, Grants and Other Similar Amounts	1	а	Federated campaigns	1a						
Gra		b	Membership dues	1b						
ts, (		С	Fundraising events	1c						
ia gi		d	Related organizations	1d						
ns,			Government grants (contribut							
er S		f	All other contributions, gifts, gran							
ig ¥			similar amounts not included abo	ve <b>1f</b>		824,480.				
dit		g	Noncash contributions included in lines	s 1a-1f: \$		<u> 246,765</u> .				
<u>a</u> C		h	Total. Add lines 1a-1f				824,480.			
						Business Code				
/ice	2	а			_					
er.		b			_					
m S		С			_					
gra		d			_					
Program Service Revenue		e			_					
_			All other program service reve							
_	_		Total. Add lines 2a-2f							
	3		Investment income (including			· ·	5,481.			5,481.
			other similar amounts)				3,401.			3,401.
	4		Income from investment of ta	· ·	-	1				
	5		Royalties							
	6	_	Cross rents	(i) Real		(ii) Personal				
	О		Gross rents							
			Less: rental expenses Rental income or (loss)							
			Net rental income or (loss)			<b>•</b>				
	7		Gross amount from sales of	(i) Securiti		(ii) Other				
	'	а	assets other than inventory	239,16		(ii) Other				
		h	Less: cost or other basis	233710						
		U	and sales expenses	244.47	5.					
		_	and sales expenses	-5.30	6.					
		ч	Net gain or (loss)	- 7	-		-5,306.	-5,306.		
o)	Q		Gross income from fundraisin				-,	, , ,		
nu	Ŭ	_	including \$	•	`					
eve			contributions reported on line							
r R			Part IV, line 18		а					
Other Revenue		b	Less: direct expenses							
0			Net income or (loss) from fund			<b>&gt;</b>				
	9		Gross income from gaming a	J		-				
			Part IV, line 19							
		b	Less: direct expenses							
			Net income or (loss) from gan							
	10		Gross sales of inventory, less							
			and allowances		a					
		b	Less: cost of goods sold		b					
		С	Net income or (loss) from sale	es of inventor	y					
			Miscellaneous Revenu			Business Code				
	11	а			]					
		b								
		С								
			All other revenue							
		е	Total. Add lines 11a-11d			<b>&gt;</b>		_		
20000	12		Total revenue. See instructions.			<b>&gt;</b>	824,655.	-5,306.	0.	· · ·
33200 10-29	ษ -13									Form <b>990</b> (2013)

### Part IX | Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A). Check if Schedule O contains a response or note to any line in this Part IX (A) Total expenses (B) (D) Do not include amounts reported on lines 6b. Management and general expenses Program service Fundraising 7b, 8b, 9b, and 10b of Part VIII. expenses expenses Grants and other assistance to governments and 288,284. 288,284. organizations in the United States. See Part IV, line 21 Grants and other assistance to individuals in the United States. See Part IV, line 22 Grants and other assistance to governments. organizations, and individuals outside the 9,488 9,488 United States. See Part IV, lines 15 and 16 Benefits paid to or for members Compensation of current officers, directors, trustees, and key employees ..... Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and 4,692. 182,846. 139,542. 38,612. persons described in section 4958(c)(3)(B) 14,976. 205,246. 190,270. Other salaries and wages ..... 7 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) Other employee benefits 21,126. 19,463. 1,663. 9 27,602. 23,056. 1,462. 3,084. Payroll taxes 10 Fees for services (non-employees): Management 28,894. 28,894. С Accounting Professional fundraising services. See Part IV. line 17 Investment management fees \_\_\_\_\_ Other. (If line 11g amount exceeds 10% of line 25, -46,368. -46,368.column (A) amount, list line 11g expenses on Sch O.) 12 Advertising and promotion 8,626. 11,737. 22,552. 2,189. 13 Office expenses Information technology ..... 14 15 Royalties 16 Occupancy 17 Travel 18 Payments of travel or entertainment expenses for any federal, state, or local public officials Conferences, conventions, and meetings ..... 19 20 Payments to affiliates 21 22 Depreciation, depletion, and amortization ..... 3,827. 3,827. 23 Other expenses. Itemize expenses not covered 24 above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule 0.) 16,385. 6,334. 9,753. 298. TRANSPORTATION TRAINING AND EDUCATION 10,913. 6,155. 4,758. 10,771. 4,984. 4,787. DUES & FEES 1,000. <u>7,277.</u> 8,252. TELEPHONE 675. 300. 7,111. 7,134. 23. All other expenses 664,222. 796,952. 82,489. 50,241. Total functional expenses. Add lines 1 through 24e 25 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here

Form **990** (2013)

if following SOP 98-2 (ASC 958-720)

Form 990 (2013)

Part X | Balance Sheet

Pai	rt X	Balance Sheet			
		Check if Schedule O contains a response or note to any line in this Part X			
			<b>(A)</b> Beginning of year		<b>(B)</b> End of year
	1	Cash - non-interest-bearing		1	
	2	Savings and temporary cash investments	1,869,007.	2	1,874,604
	3	Pledges and grants receivable, net		3	
	4	Accounts receivable, net	37,186.	4	21,828
	5	Loans and other receivables from current and former officers, directors,			
		trustees, key employees, and highest compensated employees. Complete			
		Part II of Schedule L		5	
	6	Loans and other receivables from other disqualified persons (as defined under			
		section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing			
		employers and sponsoring organizations of section 501(c)(9) voluntary			
ţ		employees' beneficiary organizations (see instr). Complete Part II of Sch L		6	
Assets	7	Notes and loans receivable, net		7	
∢	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges	3,592.	9	12,118
	10a	Land, buildings, and equipment: cost or other			
		basis. Complete Part VI of Schedule D 10a			
	b	Less: accumulated depreciation10b		10c	
	11	Investments - publicly traded securities		11	
	12	Investments - other securities. See Part IV, line 11		12	
	13	Investments - program-related. See Part IV, line 11		13	
	14	Intangible assets		14	
	15	Other assets. See Part IV, line 11		15	
	16	Total assets. Add lines 1 through 15 (must equal line 34)	1,909,785.	16	1,908,550
	17	Accounts payable and accrued expenses	29,938.	17	23,478
	18	Grants payable	60,500.	18	38,815
	19	Deferred revenue		19	
	20	Tax-exempt bond liabilities		20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
es	22	Loans and other payables to current and former officers, directors, trustees,			
Ě		key employees, highest compensated employees, and disqualified persons.			
Liabilities		Complete Part II of Schedule L		22	
_	23	Secured mortgages and notes payable to unrelated third parties		23	
	24	Unsecured notes and loans payable to unrelated third parties		24	
	25	Other liabilities (including federal income tax, payables to related third			
		parties, and other liabilities not included on lines 17-24). Complete Part X of			
		Schedule D		25	
	26	Total liabilities. Add lines 17 through 25	90,438.	26	62,293
		Organizations that follow SFAS 117 (ASC 958), check here ▶ X and			
es		complete lines 27 through 29, and lines 33 and 34.			
anc	27	Unrestricted net assets	849,083.	27	911,867
Bal	28	Temporarily restricted net assets	970,264.	28	934,390
p	29	Permanently restricted net assets		29	
Fu		Organizations that do not follow SFAS 117 (ASC 958), check here ▶└─			
ŏ		and complete lines 30 through 34.			
sets	30	Capital stock or trust principal, or current funds		30	
Ass	31	Paid-in or capital surplus, or land, building, or equipment fund		31	
Net Assets or Fund Balances	32	Retained earnings, endowment, accumulated income, or other funds	1 040 045	32	1 046 055
2	33	Total net assets or fund balances	1,819,347.	33	1,846,257
	34	Total liabilities and net assets/fund balances	1,909,785.	34	1,908,550.

Pa	rt XI Reconciliation of Net Assets				
	Check if Schedule O contains a response or note to any line in this Part XI		<u></u>		Ш
1	Total revenue (must equal Part VIII, column (A), line 12)	1			55.
2	Total expenses (must equal Part IX, column (A), line 25)	2			52.
3	Revenue less expenses. Subtract line 2 from line 1	3			03.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,81		
5	Net unrealized gains (losses) on investments	5		-7	93.
6	Donated services and use of facilities	6			
7	Investment expenses	7			
8	Prior period adjustments	8			
9	Other changes in net assets or fund balances (explain in Schedule O)	9			0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33,				
	column (B))	10	1,84	<u>6,2</u>	<u>57.</u>
Pa	rt XII Financial Statements and Reporting				
	Check if Schedule O contains a response or note to any line in this Part XII				
				Yes	No
1	Accounting method used to prepare the Form 990:  Cash X Accrual Cther				
	If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule	Ο.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		2a		X
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewer	d on a			
	separate basis, consolidated basis, or both:				
	Separate basis Consolidated basis Both consolidated and separate basis				
b	Were the organization's financial statements audited by an independent accountant?		2b	X	<u> </u>
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	e basis,			
	consolidated basis, or both:				
	Separate basis Consolidated basis Both consolidated and separate basis				
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the	e audit,			
	review, or compilation of its financial statements and selection of an independent accountant?		2c	Х	<u> </u>
	If the organization changed either its oversight process or selection process during the tax year, explain in Sch	edule O.			
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Si	ngle Audit			
	Act and OMB Circular A-133?		За		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requ				
	or audits, explain why in Schedule O and describe any steps taken to undergo such audits		3b		1

### **SCHEDULE A**

Department of the Treasury

Internal Revenue Service

(Form 990 or 990-EZ)

**Public Charity Status and Public Support** Complete if the organization is a section 501(c)(3) organization or a section

4947(a)(1) nonexempt charitable trust.

➤ Attach to Form 990 or Form 990-EZ.

► Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

Inspection

Name of the organization

THE BARTH SYNDROME FOUNDATION, INC. **Employer identification number** 22-3755704

Pa	πı	Reason	for Public Char	ity Status (All organiz	ations mu	st complet	e this part	) See inst	ructions.						
Γhe	organ	ization is not a	a private foundation	because it is: (For lines 1	I through <sup>-</sup>	11, check	only one b	ox.)							
1	Ш	A church, cor	nvention of churches	s, or association of churc	ches desc	ribed in <b>se</b>	ction 170	(b)(1)(A)(i)							
2		A school des	cribed in section 17	<b>0(b)(1)(A)(ii).</b> (Attach Sc	hedule E.)										
3		A hospital or	a cooperative hospi	tal service organization o	described	in <b>section</b>	170(b)(1)	A)(iii).							
4		A medical res	search organization of	operated in conjunction	with a hos	pital desc	ribed in <b>se</b>	ction 170	(b)(1)(A)(ii	i). Enter	the	hospital	's nam	ie,	
		city, and state	e:												
5		An organizati	on operated for the	benefit of a college or ur	niversity ov	wned or op	perated by	a governi	mental uni	t describ	ed i	in			
			(b)(1)(A)(iv). (Comple		•	•									
6				ent or governmental unit	t describe	d in <b>sectio</b>	n 170(b)(1	I)(A)(v).							
7	X	•		eives a substantial part					r from the	general	pub	olic desc	ribed i	n	
			<b>b)(1)(A)(vi).</b> (Comple				9			9	J				
8		A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.)  An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from													
9															
Ū		activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment													
		income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975.													
			<b>509(a)(2).</b> (Complete	•		л, потгы	0111000000	ioquirea b	y the orga	mzation	uite	or durie c	,0, 101	0.	
10				perated exclusively to te	st for nubl	ic safety 9	See <b>sectio</b>	n 509(a)(4	ı)						
11	$\Box$	ŭ		perated exclusively for the	•	•			•	, out the	ווות ב	rnnses r	of one	or	
••		ŭ		ations described in section						•	•	•		01	
			•		, , ,	•	, , ,	.). Occ <b>3cc</b>	).tioi1 505(t	<b>4)(O).</b> On	COR	tile box	triat		
	describes the type of supporting organization and complete lines 11e through 11h.  a Type I b Type II c Type III - Functionally integrated d Type III - Non-functionally integrated														
е		* -	-	t the organization is not	•	•	•		• • •				•	•	
·		, 0	,	han one or more publicly		,	,	,		•	•				
f				ten determination from t						/(α)(1) Οι	300	,11011 000	,(α)( <u></u> ).		
•		•	rganization, check th			•									
~			,	nis box organization accepted ar											
g		-		irectly controls, either al			•				,		Yes	No	
				upported organization?								11g(i)	103	110	
				described in (i) above?								11g(ii)			
				person described in (i) of								11g(iii)		_	
h				about the supported or								119(111)			
		1 Tovide the N	ollowing information	about the supported of	garnzation	(3).									
/:\	Nomo	of ournarted	/v::	\ Amount	of mou	noton/									
(1)		of supported anization	(ii) EIN		(iv) Is the o in col. (i) lis		organizat		(vi) Is organizatio (i) organiz	n in col.	(VII	Amount (	or mor port	ietai y	
	o, ge	an Education		above or IRC section	governing	document?	(i) of your	support?	U.S.	?		опр	Port		
				(see instructions))	Yes	No	Yes	No	Yes	No					
Γota	al														

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule A (Form 990 or 990-EZ) 2013

332021 09-25-13

### Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Sec	ction A. Public Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2009	<b>(b)</b> 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")	694,771.	769,756.	706,090.	871,480.	824,480.	3,866,577.
2	Tax revenues levied for the organ-						
	ization's benefit and either paid to						
	or expended on its behalf						
3	The value of services or facilities						
	furnished by a governmental unit to						
	the organization without charge						
4	Total. Add lines 1 through 3	694,771.	769,756.	706,090.	871,480.	824,480.	3,866,577.
5	The portion of total contributions						
	by each person (other than a						
	governmental unit or publicly						
	supported organization) included						
	on line 1 that exceeds 2% of the						
	amount shown on line 11,						
	column (f)						1,545,026.
6	Public support. Subtract line 5 from line 4.						2,321,551.
Sec	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in) 🕨	(a) 2009	<b>(b)</b> 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7	Amounts from line 4	694,771.	769,756.	706,090.	871,480.	824,480.	3,866,577.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties						
	and income from similar sources	59,232.	26,121.	11,094.	7,975.	175.	104,597.
9	Net income from unrelated business						
	activities, whether or not the						
	business is regularly carried on						
10	Other income. Do not include gain						
	or loss from the sale of capital						
	assets (Explain in Part IV.)						
11	<b>Total support.</b> Add lines 7 through 10						3,971,174.
12	Gross receipts from related activities,	etc. (see instruction	ons)			12	
13	First five years. If the Form 990 is for	r the organization's	s first, second, thir	d, fourth, or fifth ta	ax year as a sectio	n 501(c)(3)	
	organization, check this box and stop	here					<b>&gt;</b>
Sec	ction C. Computation of Publ	ic Support Pe	rcentage				
14	Public support percentage for 2013 (	line 6, column (f) di	ivided by line 11, c	olumn (f))		14	58.46 %
15	Public support percentage from 2012	Schedule A, Part	II, line 14			15	58.69 %
16a	33 1/3% support test - 2013. If the	organization did no	t check the box o	n line 13, and line	14 is 33 1/3% or n	nore, check this bo	
	stop here. The organization qualifies	as a publicly supp	orted organization				<b>▶</b> X
b	33 1/3% support test - 2012. If the	organization did no	t check a box on I	ine 13 or 16a, and	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization qual	lifies as a publicly s	supported organiza	ation			▶□
17a	10% -facts-and-circumstances tes	<b>t - 2013.</b> If the org	anization did not c	heck a box on line	e 13, 16a, or 16b, a	and line 14 is 10%	or more,
	and if the organization meets the "fac	ts-and-circumstan	ces" test, check th	nis box and <b>stop h</b>	ere. Explain in Par	t IV how the organ	ization
	meets the "facts-and-circumstances"	test. The organiza	tion qualifies as a	publicly supported	d organization		▶□
b	10% -facts-and-circumstances tes	<b>t - 2012.</b> If the org	anization did not c	heck a box on line	e 13, 16a, 16b, or	17a, and line 15 is	10% or
	more, and if the organization meets the	he "facts-and-circu	mstances" test, ch	neck this box and	<b>stop here.</b> Explain	in Part IV how the	
	organization meets the "facts-and-circ	cumstances" test.	The organization of	qualifies as a publi	cly supported orga	anization	
18	Private foundation. If the organization	on did not check a	box on line 13, 16	a, 16b, 17a, or 17b	o, check this box a		
						dule A (Form 990	

332022 09-25-13

### Part III | Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support	now, prodec com	proto r art my				
Calendar year (or fiscal year beginning in)	(a) 2009	<b>(b)</b> 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
<b>1</b> Gifts, grants, contributions, and		, , , , , , , , , , , , , , , , , , ,	, ,	` '		.,
membership fees received. (Do not						
include any "unusual grants.")						
2 Gross receipts from admissions,						
merchandise sold or services per-						
formed, or facilities furnished in						
any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that						
are not an unrelated trade or bus-						
iness under section 513						
4 Tax revenues levied for the organ-						
ization's benefit and either paid to						
or expended on its behalf						
5 The value of services or facilities						
furnished by a governmental unit to						
the organization without charge						
6 Total. Add lines 1 through 5						
<b>7a</b> Amounts included on lines 1, 2, and						
3 received from disqualified persons						
<b>b</b> Amounts included on lines 2 and 3 received						
from other than disqualified persons that						
exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
<b>c</b> Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6.)						
Section B. Total Support						
Calendar year (or fiscal year beginning in)	(a) 2009	<b>(b)</b> 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6		, , , , , , , , , , , , , , , , , , ,	, ,	, ,		.,
<b>10a</b> Gross income from interest,						
dividends, payments received on						
securities loans, rents, royalties and income from similar sources						
<b>b</b> Unrelated business taxable income						
(less section 511 taxes) from businesses						
acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business						
activities not included in line 10b, whether or not the business is						
regularly carried on						
12 Other income. Do not include gain						
or loss from the sale of capital						
assets (Explain in Part IV.)						
<b>14 First five years.</b> If the Form 990 is for	the organization's	s first, second, thir	d, fourth, or fifth t	ax vear as a sectic	on 501(c)(3) organiz	ation.
check this box and <b>stop here</b>	•		•	•		
Section C. Computation of Publi	c Support Pe	rcentage				
15 Public support percentage for 2013 (li	ne 8, column (f) d	livided by line 13, o	column (f))		15	%
16 Public support percentage from 2012	Schedule A, Part	III, line 15			16	%
Section D. Computation of Inves	tment Incom	e Percentage				
17 Investment income percentage for 20	13 (line 10c, colur	mn (f) divided by lir	ne 13, column (f))		17	%
18 Investment income percentage from 2	:012 Schedule A,	Part III, line 17			18	%
19a 33 1/3% support tests - 2013. If the					33 1/3%, and line 1	7 is not
more than 33 1/3%, check this box ar	nd <b>stop here.</b> The	e organization qual	ifies as a publicly	supported organiz	ation	▶□
b 33 1/3% support tests - 2012. If the	organization did r	not check a box or	line 14 or line 19	a, and line 16 is mo	ore than 33 1/3%,	and
line 18 is not more than 33 1/3%, chec	ck this box and <b>s</b>	<b>top here.</b> The orga	anization qualifies	as a publicly supp	orted organization	
20 Private foundation. If the organization	า did not check a	box on line 14, 19	a, or 19b, check t	his box and see in:	structions	<u> </u>

art IV	Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12.
	Also complete this part for any additional information. (See instructions).

### SCHEDULE D

(Form 990)

Department of the Treasury Internal Revenue Service

## Supplemental Financial Statements

Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b. Attach to Form 990.

Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990

OMB No. 1545-0047

Inspection

**Employer identification number** Name of the organization THE BARTH SYNDROME FOUNDATION, 22-3755704 Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the Part I organization answered "Yes" to Form 990. Part IV. line 6. (a) Donor advised funds (b) Funds and other accounts Total number at end of year \_\_\_\_\_ 1 2 Aggregate contributions to (during year) 3 Aggregate grants from (during year) Aggregate value at end of year 4 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? Part II Conservation Easements. Complete if the organization answered "Yes" to Form 990, Part IV, line 7. Purpose(s) of conservation easements held by the organization (check all that apply). Preservation of land for public use (e.g., recreation or education) Preservation of an historically important land area Protection of natural habitat Preservation of a certified historic structure Preservation of open space Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year. Held at the End of the Tax Year Total number of conservation easements 2a Total acreage restricted by conservation easements 2b Number of conservation easements on a certified historic structure included in (a) Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax 3 vear -Number of states where property subject to conservation easement is located > Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year 6 Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year > \$ Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements. Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" to Form 990, Part IV, line 8. 1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items. b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items: (i) Revenues included in Form 990, Part VIII, line 1 (ii) Assets included in Form 990, Part X If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items: a Revenues included in Form 990, Part VIII, line 1 Assets included in Form 990, Part X

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule D (Form 990) 2013

**b** Permanent endowment %

c Temporarily restricted endowment ▶ \_\_\_\_\_%

The percentages in lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

(i) unrelated organizations

(ii) unrelated organizations

(iii) unrelated organizations

(ii) related organizations

(iii) related organizations

3a(ii)

b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

4 Describe in Part XIII the intended uses of the organization's endowment funds.

#### Part VI | Land, Buildings, and Equipment.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11a. See Form 990, Part X, line 10

	Complete if the organization answered "Yes" to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.									
	Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value					
1a	Land									
b	Buildings									
	Leasehold improvements									
d	Equipment									
<u>e</u>	Other									
Total	Add lines 1a through 1e (Column (d) must equa	ol Form 990 Part X colur	mn (R) line 10(c) )		0.					

Schedule D (Form 990) 2013

No

	(Form 990) 2013		 FOUNDATION,	INC.	22-3755704
art VIII	Investments -	Other Securities.			

	Complete if the organization answered "Yes"				
· ·	tion of security or category (including name of security)	(b) Book value	(c) Method of	valuation: Cost or e	end-of-year market value
	al derivatives				
	held equity interests				
3) Other					
(A)					
(B)					
(C)					
(D)					
(E)					
(F) (G)					
(H)					
	b) must equal Form 990, Part X, col. (B) line 12.)				
	Investments - Program Related.	1			
	Complete if the organization answered "Yes"	to Form 990 Part IV line	11c See Form 990	Part X line 13	
	(a) Description of investment	(b) Book value			end-of-year market value
(1)			.,		-
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
	b) must equal Form 990, Part X, col. (B) line 13.)				
Part IX	Other Assets.				
	Complete if the organization answered "Yes"		11d. See Form 990,	Part X, line 15.	1
	(a)	Description			(b) Book value
(1)					
(2)					
(3)					
(4)					
(5)					
(6) (7)					
(1)					
(8)					
(8)					
(9)	mn (b) must equal Form 990, Part X, col. (B) lin	ne 15.)			<b>&gt;</b>
(9)	mn (b) must equal Form 990, Part X, col. (B) lin	e 15.)			>
(9) otal. (Colu	Other Liabilities.			m 990, Part X, line	25.
(9) otal. (Colu Part X		to Form 990, Part IV, line		m 990, Part X, line	25.
(9) Fotal. (Colu. Part X	Other Liabilities.  Complete if the organization answered "Yes"	to Form 990, Part IV, line	11e or 11f. See Forr	n 990, Part X, line	25.
(9) otal. (Colu. Part X	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	m 990, Part X, line	25.
(9) Fotal. (Column Part X  . (1) Fed	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	m 990, Part X, line	25.
(9) Fotal. (Columbia Part X  (1) Fed (2)	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	n 990, Part X, line	25.
(9) Fotal. (Columbrate X)  (1) Fed (2) (3)	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	n 990, Part X, line	25.
(9)  Fotal. (Columnation (Colum	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	n 990, Part X, line	25.
(9) Fotal. (Columnation (Column	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	m 990, Part X, line	25.
(9)  otal. (Columnation of the columnation of the c	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability	to Form 990, Part IV, line	11e or 11f. See Forr	m 990, Part X, line	25.
(9)  otal. (Columnal (Columna) (Columnal (Columna) (Columnal (Columna) (Columna) (Columnal (Columna) (Columnal (Columna) (Colu	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability  deral income taxes	to Form 990, Part IV, line	11e or 11f. See Forr	n 990, Part X, line	25.
(9)  otal. (Column  Part X  (1) Fed  (2)  (3)  (4)  (5)  (6)  (7)  (8)  (9)  otal. (Column  otal. (Column	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability  eral income taxes  mn (b) must equal Form 990, Part X, col. (B) lim	to Form 990, Part IV, line	11e or 11f. See Forr (b) Book value		
(9)  otal. (Column (Co	Other Liabilities.  Complete if the organization answered "Yes"  (a) Description of liability  deral income taxes	to Form 990, Part IV, line	11e or 11f. See Forr (b) Book value	financial statemen	ts that reports the

Sche	dule D (Form 990) 2013 THE BARTH SYNDROME FOUNDAT	ION. IN	C.	22-3	755704 Page <b>4</b>
	t XI Reconciliation of Revenue per Audited Financial Stateme				reger
	Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.		•		
1	· · · · · · · · · · · · · · · · · · ·			1	823,862.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
а	Net unrealized gains on investments	2a	-793 <b>.</b>		
b	Donated services and use of facilities	2b			
С	Recoveries of prior year grants				
d	Other (Describe in Part XIII.)				
е	Add lines 2a through 2d			2e	-793 <b>.</b>
3	Subtract line 2e from line 1			3	824,655.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:				
а	Investment expenses not included on Form 990, Part VIII, line 7b	. 4a			
b	Other (Describe in Part XIII.)	. 4b			
	Add lines <b>4a</b> and <b>4b</b>			4c	0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)			824,655.	
Pai	t XII Reconciliation of Expenses per Audited Financial Statem	nents With I	Expenses per	Return	1.
	Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.				
1	Total expenses and losses per audited financial statements			1	796,952.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:				
а	Donated services and use of facilities	. 2a			
b	Prior year adjustments	2b			
С	Other losses	. 2c			
d	Other (Describe in Part XIII.)	. 2d			
е	Add lines 2a through 2d			2e	0.
3	Subtract line 2e from line 1			3	796,952.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:				
а	Investment expenses not included on Form 990, Part VIII, line 7b	. 4a			
b	Other (Describe in Part XIII.)	. 4b			
С	Add lines 4a and 4b			4c	0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)			5	796,952.

Part XIII	Supplemental Inf	ormation.
-----------	------------------	-----------

ines 20 and 4b, and Part Air, lines 20 and 4b. Also complete this part to provide any additional information.					

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI,

### **SCHEDULE F** (Form 990)

### **Statement of Activities Outside the United States**

► Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

➤ Attach to Form 990. ➤ See separate instructions.

Employer identification number

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

Name of the organization

▶ Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

Open to Public Inspection

$_{ m THI}$	E BARTH SYNDR	OME FOUN	DATION,	INC.		22-37557	04
Pa	rt I General Info	rmation on A	ctivities Ou	tside the United States. Comple	te if the organ		
	Form 990, Part IV	V, line 14b.					
1				ds to substantiate the amount of its gra			] <b>v</b> ]
	the grantees' eligibility for	or the grants or a	assistance, and	the selection criteria used to award the	grants or assi	stance? L	Yes X No
2	United States.		-	procedures for monitoring the use of its	-	ther assistance ou	tside the
3				an be duplicated if additional space is n			1
	(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	is a prog describe	vity listed in (d) gram service, e specific type ce(s) in region	(f) Total expenditures for and investments in region
NOR	TH AMERICA	0	0	RESEARCH GRANT AWARDED			18,975.
3 a	Sub-total	0	0				18,975.
	Total from continuation sheets to Part I	0	0				0.
С	Totals (add lines 3a and 3b)	0	0				18,975.
НΔ	For Panerwork Reduct	ion Act Notice	can the Instruc	tions for Form 990		Schodulo E	(Form 990) 2013

14010414 756282 06158-000

Part II	Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any
	recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)		(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			RELATIONSHIP BETWEEN MEMBRANE PHYSICAL PROPERTIES AND THE					
		NORTH AMERICA	ACTION OF TAFAZZIN.	9,488.	СНЕСК	0.		
2 Enter total number of	recipient organizatio	ns listed above that are	recognized as charities by the	foreign country	recognized as tax-e	xempt by		

2	Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by
	the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3 Enter total number of other organizations or entities

\_\_\_\_\_<u>1</u>\_\_\_\_\_0

Schedule F (Form 990) 2013

Part III Grants and Other Assistan Part III can be duplicated if a			ates. Complete i	tine organization answered "Yes"	on Form 990, Part	Tiv, line 16.	
(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)

### Schedule F (Form 990) 2013 Part IV | Foreign Forms

1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)	Yes	X No
2	Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)	Yes	X No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations. (see Instructions for Form 5471)	Yes	X No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)	Yes	X No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect To Certain Foreign Partnerships. (see Instructions for Form 8865)	Yes	X No
6	Did the organization have any operations in or related to any boycotting countries during the tax year? If "Yes," the organization may be required to file Form 5713, International Boycott Report. (see Instructions for Form 5713)	Yes	X No

Schedule F (Form 990) 2013

#### Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c)

(estimated number of recipients), as applicable. Also complete this part to provide any additional information.
PART I, LINE 2:
EXPLANATION: PRIOR TO MAKING ANY PAYMENT, WE REQUIRE CERTIFICATION OF THE
USE OF FUNDS FROM THE CONTRACTING OFFICER OF THE INSTITUTION RECEIVING
THE GRANT ON BEHALF OF THE GRANT RECIPIENT. EVERY SIX MONTHS THEREAFTER,
AND PRIOR TO ANY SUBSEQUENT PAYMENTS, THE CERTIFYING OFFICER OF THE
INSTITUTION AND THE GRANT RECIPIENT MUST SIGN A DOCUMENT CERTIFYING THAT
THE RESEARCH IS CONTINUING AS PLANNED AND THAT REASONABLE PROGRESS IS
BEING MADE IN ACCORDANCE WITH THE ORIGINAL PROPOSAL. FOLLOWING COMPLETION
OF THE WORK, A SUMMARY OF THE RESEARCH RESULTS IS REQUIRED TO BE SENT TO
US AS WELL AS ANY PUBLISHED FINDINGS.

### SCHEDULE I (Form 990)

Department of the Treasury Internal Revenue Service **Grants and Other Assistance to Organizations, Governments, and Individuals in the United States** 

Complete if the organization answered "Yes" to Form 990, Part IV, line 21 or 22.

➤ Attach to Form 990.

► Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990

OMB No. 1545-0047

Open to Public Inspection

Name of the organization	CANDDOME	E FOUNDATION	I TNC		-		Employer identification number $22-3755704$
Part I General Information on Grants a		FOUNDATION	i, inc.				22-3733704
Does the organization maintain records criteria used to award the grants or assi     Describe in Part IV the organization's pro	stance?					sistance, and the selec	
Part II Grants and Other Assistance to	Governments an	d Organizations in th	e United States. C	Complete if the org	anization answered "	Yes" to Form 990, Part	IV, line 21, for any
recipient that received more than	\$5,000. Part II car	n be duplicated if addit		ded.	(f) Method of		,
(a) Name and address of organization or government	( <b>b)</b> EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
NY UNIVERSITY MEDICAL CENTER							RESEARCH
550 FIRST AVENUE							
NEW YORK, NY 10016		N/A	40,000.	0.			
UNIVERISTY OF IOWA 2222 OLD HIGHWAY 218 S							
IOWA CITY, IA 52242		N/A	40,000.	0.			RESEARCH
CHILDREN'S HOSPITAL AND RESEARH CENTER AT OAKLAND - 747 52ND STREET - OAKLAND, CA 94609	94-0382330	501(C)(3)	40,000.	0.			RESEARCH
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	40,000.	0.			RESEARCH
UNIVERISTY OF WASHINGTON 4311 11TH AVE NE, STE 100 SEATTLE, WA 98105	91-6001537		40,000.	0.			RESEARCH
UNIVERSITY OF WASHINGTON 700 ROSEDALE AVE, BOX 1034 ST LOUIS, MO 63112-1408	43-0653611	N/A	0.	0.			RESEARCH
2 Enter total number of section 501(c)(3) a	nd government o	rganizations listed in th	ne line 1 table				<b>&gt;</b>
3 Enter total number of other organization	s listed in the line	1 table					<b>&gt;</b>
LHA For Paperwork Reduction Act Notice	, see the Instruc	tions for Form 990.					Schedule I (Form 990) (2013)

Part II Continuation of Grants and Other	Assistance to Go	vernments and Orga	nizations in the U	nited States (Sch	edule I (Form 990), Pa	rt II.)	
(a) Name and address of organization or government	( <b>b)</b> EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
ENNEDY KRIEGER INSTITUTE							
707 NORTH BROADWAY							
BALTIMORE, MD 21205	52-1524965	501(C)(3)	0.	0.			RESEARCH
,							
UNIVERSITY OF CALIFORNIA AT SAN							
DIEGO - 9500 GILMAN DRIVE - LA							
OLLA, CA 92093	95-6006144		0.	0.			RESEARCH
PENNSYLVANIA STATE UNIVERSITY							
SCHOOL OF MEDICINE - 500							
JNIVERSITY DRIVE - HERSHEY, PA							
17033	25-1854772	501(C)(3)	40,000.	0.			RESEARCH
COLORADO STATE UNIVERSITY							
1062 CAMPUS DELIVERY							
FORT COLLINS, CO 80523-1062		N/A	40,000.	0.			RESEARCH
			1				

Part III Grants and Other Assistance to Individuals in the Unit Part III can be duplicated if additional space is needed.	ted States. Com	plete if the organiza	ation answered "Yes	to Form 990, Part IV, line 22.	-
(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non- cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
Part IV   Supplemental Information. Provide the information req	uired in Part I, lin	e 2, Part III, column	ı (b), and any other a	dditional information.	
PART I, LINE 2:					
EXPLANATION: PRIOR TO MAKING ANY P	AYMENT,	WE REQUIRE	CERTIFICA	TION OF THE	
USE OF FUNDS FROM THE CONTRACTING	OFFICER	OF THE INS	TITUTION R	ECEIVING THE	
GRANT ON BEHALF OF THE GRANT RECIP	IENT. EV	ERY SIX MC	NTHS THERE	AFTER, AND	
PRIOR TO ANY SUBSEQUENT PAYMENTS,	THE CERT	IFYING OFF	CICER OF TH	E INSTITUTION	
AND THE GRANT RECIPIENT MUST SIGN	A DOCUME	NT CERTIFY	ING THAT T	HE RESEARCH	
IS CONTINUING AS PLANNED AND THAT	REASONAB	LE PROGRES	S IS BEING	MADE IN	
ACCORDANCE WITH THE ORIGINAL PROPO	SAL. FOL	LOWING COM	IPLETION OF	THE WORK, A	
SUMMARY OF THE RESEARCH RESULTS IS	REOUTRE	D TO BE SE	NT TO US A	S WELL AS ANY	

Schedule I (Form 990) Part IV Supplemental Inf	THE	BARTH	SYNDROME	FOUNDATION,	INC.	22-3755704 Page 2
Part IV Supplemental Inf	ormatio	on				
PUBLISHED FINDINGS	5.					

### SCHEDULE J (Form 990)

Department of the Treasury

**Compensation Information** 

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

Complete if the organization answered "Yes" on Form 990, Part IV, line 23.

Attach to Form 990. See separate instructions.

► Information about Schedule J (Form 990) and its instructions is at www.irs.gov/form990

OMB No. 1545-0047

Open to Public Inspection

Name of the organization

THE BARTH SYNDROME FOUNDATION, INC.

Employer identification number 22-3755704

Pa	art I Questions Regarding Compensation			
			Yes	No
1a	Check the appropriate box(es) if the organization provided any of the following to or for a person listed in Form 990,			
	Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.			
	First-class or charter travel Housing allowance or residence for personal use			
	Travel for companions Payments for business use of personal residence			
	Tax indemnification and gross-up payments Health or social club dues or initiation fees			
	Discretionary spending account Personal services (e.g., maid, chauffeur, chef)			
b	If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or			
	reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b		
2	Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors,			
	trustees, and officers, including the CEO/Executive Director, regarding the items checked in line 1a?	2		
3	Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's			
	CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to			
	establish compensation of the CEO/Executive Director, but explain in Part III.			
	Compensation committee Written employment contract			
	Independent compensation consultant  Compensation survey or study			
	Form 990 of other organizations  Approval by the board or compensation committee			
4	During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing			
	organization or a related organization:			
а	Receive a severance payment or change-of-control payment?	4a		X
b	Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b		Х
С	Participate in, or receive payment from, an equity-based compensation arrangement?	4c		Х
	If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.			
_	Only section 501(c)(3) and 501(c)(4) organizations must complete lines 5-9.			
5	For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation			
	contingent on the revenues of:	_		37
	The organization?	5a		X
b	Any related organization?	5b		
	If "Yes" to line 5a or 5b, describe in Part III.			
6	For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation			
	contingent on the net earnings of:			v
	The organization?	6a		X
b	Any related organization?	6b		
_	If "Yes" to line 6a or 6b, describe in Part III.			
7	For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments	_		v
_	not described in lines 5 and 6? If "Yes," describe in Part III	7		X
8	Were any amounts reported in Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the			v
_	initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8		X
9	If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in			
	Regulations section 53.4958-6(c)?	9		l

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule J (Form 990) 2013

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported in Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that are not listed on Form 990, Part VII.

Note. The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

		(B) Breakdown of	W-2 and/or 1099-MI	SC compensation	(C) Retirement and other deferred	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation reported as deferred	
(A) Name and Title		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	compensation	benefits	(B)(I)-(U)	in prior Form 990	
(1) MATTHEW TOTH	(i)	143,781.	0.	0.	0.	7,209.	150,990.	0.	
DIR OF SCIENCE	(ii)	0.	0.	0.	0.	0.	0.	0.	
(2) VALERIE BOWEN	(i)	72,526.	0.	0.	0.	7,266.	79,792.	0.	
PRESIDENT, FORMER	(ii)	0.	0.	0.	0.	0.	0.	0.	
	(i)								
	(ii)								
	(i)								
	(ii)								
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	(ii)								
	(i)								
	(ii)								
	(i)								
	(ii)								
	(i)								
	(ii)								

### **SCHEDULE M** (Form 990)

**Noncash Contributions** 

Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization

Attach to Form 990.

► Information about Schedule M (Form 990) and its instructions is at www.irs.gov/form990

THE BARTH SYNDROME FOUNDATION, INC.

**Employer identification number** 22-3755704

Pai	t I Types of Property				•			
	•	(a)	(b)	(c)	(d)			
		Check if applicable	Number of contributions or	Noncash contribution amounts reported on	Method of de		•	c
		арріісаріє		Form 990, Part VIII, line 1		ation ai	nount	
1	Art - Works of art							
2	Art - Historical treasures							
3	Art - Fractional interests							
4	Books and publications							
5	Clothing and household goods							
6	Cars and other vehicles							
7	Boats and planes							
8	Intellectual property							
9	Securities - Publicly traded	X	9	246,765.	COST ON DAY	OF	DO	NAT
10	Securities - Closely held stock							
11	Securities - Partnership, LLC, or							
	trust interests							
12	Securities - Miscellaneous							
13	Qualified conservation contribution -							
	Historic structures							
14	Qualified conservation contribution - Other							
15	Real estate - Residential							
16	Real estate - Commercial							
17	Real estate - Other							
18	Collectibles							
19	Food inventory							
20	Drugs and medical supplies							
21	Taxidermy							
22	Historical artifacts							
23	Scientific specimens							
24	Archeological artifacts							
25	Other • ()							
26	Other ()							
27	Other ( )							
28	Other (							
29	Number of Forms 8283 received by the organ	zation durin	g the tax year for o	contributions	1			
	for which the organization completed Form 82						1	
							Yes	No
30a	During the year, did the organization receive b	y contribution	on any property re	oorted in Part I, lines 1 - 28	that it must hold for			
	at least three years from the date of the initial	contribution	, and which is not	required to be used for exe	empt purposes for			
	the entire holding period?					30a		X
b	If "Yes," describe the arrangement in Part II.							
31	Does the organization have a gift acceptance	policy that re	equires the review	of any non-standard contr	butions?	31		Х
32a	Does the organization hire or use third parties							
	contributions?		_	· · · · ·		32a		Х
b	If "Yes," describe in Part II.							
33	If the organization did not report an amount in	column (c) t	for a type of prope	rty for which column (a) is	checked,			
	describe in Part II.			.,				

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule M (Form 990) (2013)

Schedule M	(Form 990) (2013)	THE	BARTH	SYNDROME	FOUNDATION,	INC.	22-3755704	Page 2
Part II	Supplemental is reporting in Part this part for any ac	Infori	<b>mation.</b> Pr	ovide the informa umber of contribu	tion required by Part I, li tions, the number of iter	ines 30b, 32b ns received,	o, and 33, and whether the organiza or a combination of both. Also com	ation plete
	<u> </u>							

### SCHEDULE O (Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information.

► Attach to Form 990 or 990-EZ.

Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization

THE BARTH SYNDROME FOUNDATION, INC.

Employer identification number 22-3755704

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

ORGANIZATIONS ADDRESSING THE CAUSES, DIAGNOSIS, TREATMENT AND CURE OF BARTH SYNDROME; AND 3) TO ASSIST IN THE SUPPORT OF FAMILIES WITH

CHILDREN SUFFERING FROM BARTH SYNDROME.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

COSTS RELATING TO AWARENESS.

EXPENSES \$ 30,592. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 2:

EXPLANATION: JOHN AND SUSAN WILKINS ARE MOTHER AND SON.

FORM 990, PART VI, SECTION B, LINE 11:

EXPLANATION: THE FORM 990 IS SENT TO THE FULL BOARD OF DIRECTORS VIA EMAIL PRIOR TO BEING FILED WITH IRS. ALL DIRECTORS ARE AFFORDED THE OPPORTUNITY TO ASK QUESTIONS AND OFFER EDITS. THE DECISION OF WHETHER TO MAKE EDITS IS MADE BY THE STAFF PERSON IN CHARGE OF FINANCES WITHIN THE ORGANIZATION IN CONJUNCTION WITH CONSULTATION WITH OUR TAX PREPARER.

FORM 990, PART VI, SECTION B, LINE 12C:

EXPLANATION: EACH BOARD MEMBER AND ALL EMPLOYEES WHO CAN INFLUENCE THE

ACTIONS OF BARTH SYNDROME FOUNDATION (BSF) MUST FILL OUT AN ANNUAL

DECLARATION STATING THAT THEY HAD NO CONFLICTS OR IDENTIFYING THE NATURE OF

THEIR INTERESTED PARTY TRANSACTIONS. IT IS THE RESPONSIBILITY OF THE BOARD,

OFFICERS, AND MANAGEMENT EMPLOYEES TO SCRUTINIZE THEIR TRANSACTIONS AND

OUTSIDE BUSINESS INTERESTS AND RELATIONSHIPS FOR POTENTIAL CONFLICTS AND TO LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule O (Form 990 or 990-EZ) (2013)

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THE BARTH SYNDROME FOUNDATION, INC.

Employer identification number 22-3755704

IMMEDIATELY MAKE SUCH DISCLOSURES. THE BOARD SHALL DETERMINE WHETHER A

CONFLICT EXISTS AND IN THE CASE OF AN EXISTING CONFLICT, WHETHER THE

CONTEMPLATED TRANSACTION MAY BE AUTHORIZED AS JUST, FAIR, AND REASONABLE TO

BSF.

FORM 990, PART VI, SECTION B, LINE 15:

EXPLANATION: EACH YEAR, THE EXECUTIVE AND COMPENSATION COMMITTEES REVIEW

COMPARABLE SALARIES BASED ON A RECOGNIZED STUDY, REVIEWS INFORMATION FROM

OTHER COMPARABLE ORGANIZATIONS' 990'S, AND REVIEWS THE PERFORMANCE OF THE

EXECUTIVE DIRECTOR AND THE KEY EMPLOYEES TO DETERMINE IF THE EXISTING

SALARIES FALL WITHIN THESE RANGES. AFTER A DELIBERATION OF THIS MATTER, A

NEW PROPOSED SALARY AND BENEFIT PACKAGE IS VOTED ON. THE MINUTES OF THE

BOARD OF DIRECTORS REFLECT THE NATURE OF THIS PROCESS.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:
MA,NY,CT,NJ,IL,TN,PA,VA,CA,FL,MD,UT,GA,KS

FORM 990, PART VI, SECTION C, LINE 19:

EXPLANATION: THE FOUNDATION MAKES ITS GOVERNING DOCUMENTS, CONFLICT OF

INTEREST AND OTHER POLICIES, AND FINANCIAL STATEMENTS AVAILABLE TO THE

PUBLIC ON ITS WEBSITE AND/OR BY REQUEST.

FORM 990, PART XII, LINE 2C:

EXPLANATION: THERE HAS BEEN NO CHANGE FROM THE PRIOR YEAR IN THE

OVERSIGHT OF THE AUDIT AND SELECTION OF THE INDEPENDENT ACCOUNTANT. THE

FOUNDATION HAS AN AUDIT COMMITTEE COMPRISED OF THE CHAIRMAN, TREASURER

AND SECRETARY. THE AUDIT COMMITTEE IS RESPONSBILE FOR THE SELECTION OF

THE INDEPENDENT ACCOUNTANT AND FOR THE OVERSIGHT OF THE AUDIT OF THE

Schedule O (Form 990 or 990-EZ) (2013)